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ABSTRACT

In focus group interviews, 39 parents of children (ages birth to 21 years) with developmental disabilities, emotional disorders, and technology-supported needs shared their perspectives regarding special needs, crisis situations, and parent/professional relationships. The purpose of the study was to determine what is necessary to keep children with disabilities in their homes. The study found that 50 percent of the families reported a recent, serious crisis situation that had threatened out-of-home placement. The most frequently stated service need in all groups was for respite care, followed by special education, counseling, and information. Values such as normalization and community integration were desired. Emotional support from other parents was a key to coping. Parents believed that crises were most often caused by the child's behavior and needs, and second most often caused by the system. Each disability group had a somewhat different perspective on the general qualities most important to their relationship with professionals. Parents recognized the importance of a coordinated, holistic system of care. Parents (especially of children with emotional disorders) often felt blamed and criticized by professionals, and expressed dismay at having to be such strong self-advocates to professionals. Implications for policy and practice are spelled out. (14 references) (JDD)

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Keeping Children with Disabilities at Home: Research Results of the Parent Perspective

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PURPOSE

This document reports the results of a content analysis of focus group interviews of parents of children with developmental disabilities, emotional disorders, and technology-supported needs. These interviews took place in January 1990 in St. Paul, Minnesota. Parents shared their perspectives regarding special needs, crisis situations, and parent/professional relationships. Implications for policy and practice include targeting specific services, monitoring values of programs and staff, and minimizing system-induced crisis.

This research is part of a larger study that includes a longitudinal (18-month) look at the same families and an analysis of state laws and policies. Other reports will be forthcoming as research is completed.

RESEARCH SUMMARY

Who conducted the study?

The Beach Center on Families and Disabilities
Schiefelbusch Institute for Life Span Studies
The University of Kansas
Project Director: Chris Petr, Ph.D., Assistant Professor of Social Welfare

What was the purpose of the study?

To understand the parent perspective on what is necessary to keep children with disabilities in their homes.

How was the study conducted?

- Researchers held focus group interviews with 38 parents of children with emotional disorders (16), with developmental disabilities (15), and with medically fragile conditions requiring technology support (7).
- Content analysis of transcribed audiotapes followed.

What were the major findings?

- 50% of the families reported a recent, serious crisis situation that had threatened out-of-home placement.
- **Respite care** was the most frequently stated service need in all groups.
- Other service needs were **special education, counseling**, and **information.**

- Values such as **normalization** and **community integration** must accompany services.
- **Emotional support** from other parents is a key to coping.
- Parents believe that **crises are often caused by the system**.
- Parents (especially of children with emotional disorders) often **feel blamed and criticized by professionals**.

What are the implications for families?

- Parents, across the spectrum of disabilities, have much in common, including a shared value system, the need for services, and conflicts with the service system.

What are the implications for professionals?

- Families with children with disabilities are at high risk for crises that threaten placement.
- Services are important, but they must be delivered with a commitment to family-held values.
- The values and attitudes of programs and staff should be monitored.
- Parents should be included in the design, implementation, and evaluation of programs so professionals are more accountable to parents as consumers.

INTRODUCTION

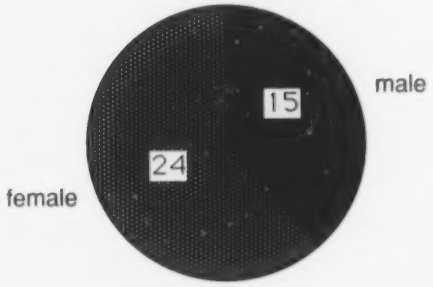
Children with disabilities present many challenges for their parents, their families, and the larger community. About 12 percent of all children have a disability (Garbarino, et al., 1987). Generally, these children are considered to be at high risk for out-of-home placement for two reasons: (a) They may be at high risk for abuse and neglect because of the high levels of stress and frustration they generate in caregivers (Garbarino, et al., 1987), and (b) parents sometimes do not feel adequately equipped to care for the special needs of the child in the home, necessitating placement in a specialized residential facility or foster home. (A recent study of 35 states estimated an average of 20.5 percent of children with disabilities are currently in foster care [Hill, et al. 1987]).

Federal funding requires local judges to certify that reasonable efforts have been made before a child can be placed in temporary state custody. Yet "reasonable efforts" is a vague term that is not formally defined, despite federal permanency planning legislation (Public Law 96-272) and the resultant reasonable efforts to maintain abused, neglected, and high-risk children in their families. Federal funding also requires states to document their reasonable efforts policies and procedures. Working definitions for reasonable efforts, for the most part, emphasize the need

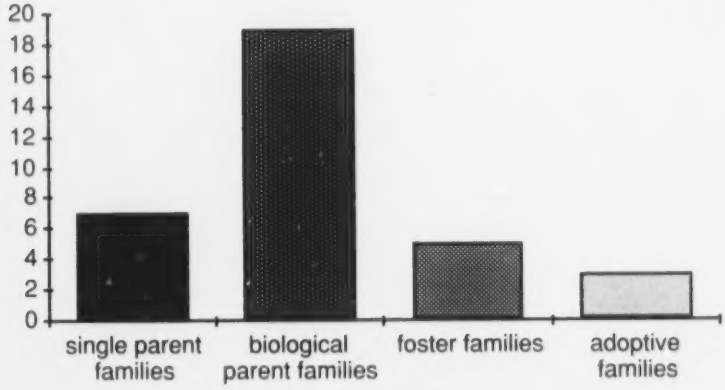
for provision of various services and procedural accountability (Alsop, 1989; Ratterman, 1987; Seaberg, 1986). But none of these definitions addresses the particular issues for children with disabilities and their families. Just as we have acknowledged and appreciated the special needs of children with disabilities in the field of adoptions (Coyne & Brown, 1986), professionals must also consider their needs in relation to efforts to prevent out-of-home placement.

The purpose of the exploratory study reported here was to contribute to the effort to define reasonable efforts for children with disabilities by systematically obtaining data from parents themselves. Such information can provide material for subsequent research, and can enrich policies and programs by incorporating the consumer/client viewpoint.

Number of Participants



Number of Families



RESEARCH DESIGN

Focus groups—discussion groups that use group interaction to generate responses and insights that might not occur in individual interviews—were employed to measure parent opinions.

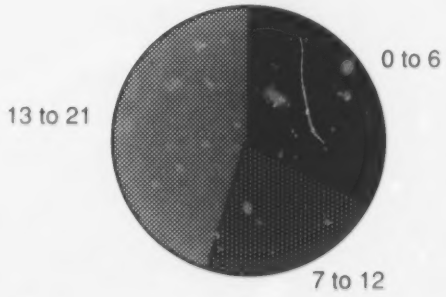
Sample

Participants were recruited to represent children with three different types of disabilities: (a) mental and developmental disabilities; (b) emotional disorders; and (c) medically fragile conditions requiring life-sustaining technology.

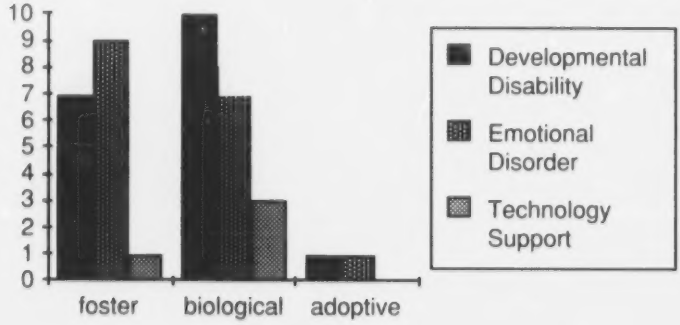
Parents were recruited through existing state service programs and disability organizations in the Minneapolis-St. Paul area. Minnesota is recognized for its progressive reasonable efforts programs (Stein & Cornstock, 1987); therefore, the sample is representative of the best situation that currently exists for these families. Their perspective on reasonable efforts in an already progressive system can help us extend, modify, and improve upon those efforts in any state system.

Focus group participants were asked to discuss these four topic areas:

Ages of Children Represented



Number of Children with Disabilities in Families Represented



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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

1. What special needs does your family have in raising a child with a disability?

2. What serious situations—crises that could have resulted in out-of-home placements—have occurred in your family in the last six months or so?

3. How did professionals respond to the serious situations? What would you consider an ideal parent/professional relationship?

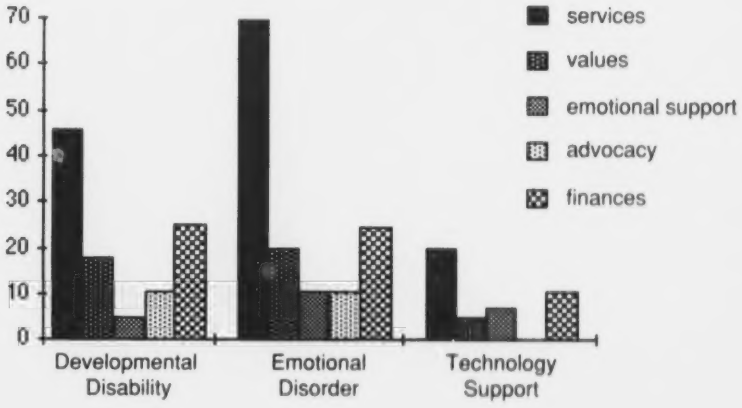
4. As a summary topic, from your perspective, define "reasonable efforts" (moderator explained use of term in legislation).

Data Analysis

Researchers used transcripts of the focus groups to conduct a content analysis. Participant statements were coded into four major categories: (a) special needs; (b) reasonable efforts in crisis situations; (c) parent/professional relationships; and (d) definition of reasonable efforts.

Statements by Parents - Special Needs

Statements by Parents - According to Disability



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SPECIAL NEEDS

Any reasonable efforts policy or program must be based on the needs of the clients. Participants made 241 statements regarding their special needs. From this total, researchers established five subcategories of responses (listed here in order of frequency): (a) pertaining to the need for a great variety of services; (b) relating to the need for the system of care to better reflect certain attitudes and values; (c) reflecting the need for emotional support; (d) relating to advocacy needs; and (e) relating to financial needs.

Special Needs—Services

All groups strongly expressed the need for an array of services. One of the needs parents mentioned most often was the need for **respite services**. One parent said:

> *It's the break that people need—just to get away once in awhile. You can put up with a lot of garbage if you can get out to dinner once in awhile.*

Most parents received respite care, but still mentioned it as essential. Parents of children with emotional disorders were the exception. These parents felt a strong need for the service but had a more difficult time obtaining it. 11

Families also voiced a need for appropriate, quality **special education programs.** Parents of children with emotional disorders were particularly focused on this issue. They lamented the insensitivity of the IEP process, the lack of information provided by school staff, and their frustration at wanting their own wishes included in the IEP rather than just the school's. Parents said they wanted programs that matched their child's needs, rather than vice-versa:

> *Too often the schools develop programs to meet kids with special needs and then they force-fit children to the programs rather than developing programs that meet those kids' needs.*

A third major service need families discussed involved **counseling services**. Parents of children with emotional disorders focused on the need for psychotherapy for the child. Parents of children with developmental disabilities emphasized the need for parent and family counseling to deal with the strains and challenges of coping with the child in the family setting. They recognized the potential for dysfunctional patterns to develop, for marriages to suffer, and for siblings to feel excluded and seek attention. Some parents also emphasized the need to constantly confront and cope with grief and loss issues.

The final major service need parents described was for **information** about available programs. Perhaps surprisingly, most parents reported that they stumbled onto programs by chance or learned about them from other parents. They suggested the development of a central clearinghouse of information ombudsman or even a computer terminal that parents could use to find out about services.

Special Needs—Values

The second most frequently mentioned subcategory of needs was the area of attitudes and values. Parents stressed the importance of integration into the community mainstream so that their children's lives could be as normal as possible. One parent of a child with an emotional disorder said:

> *School life, friends in the neighborhood, church and paper route, baseball or football in the summer: you gotta feel as much as you can like the kid next door.*

A parent of a child with technology support had this to say:

> *Even if the teachers don't know all they might need to know, but it ends up that my Katlin gets treated like the other children in the room, and that's what I like. And*

she has fun and gets into situations where she's doing group things with the other kids.

Another value theme parents expressed involved the need to treat the children as children, to avoid labels and preconceived ideas about the disability, and to "see the child and not the disability." Parents of children with developmental disabilities had this to say:

Disabled is not to do things for them or to them, but to empower them to have control over their own lives so that they're in charge, rather than to have a disability control them or an agency control them.

You don't say, "Well, the other one has brown hair and blue eyes, is that OK?" So why do you have to say, "She's in a wheelchair, is that OK?"

I discipline my handicapped kids just like my normal kids.

I think there are cases out there where it is working. I think more effort is being made to promote community inclusion. Children are learning from a younger age—they're seeing kids with disabilities they never saw before.

Special Needs—Emotional Support

The third subcategory of needs parents mentioned relates to the need for emotional support. Parents mentioned family, church, and friends as important social support systems. But parents cannot depend solely on these systems for the kind of consistent, reliable, and empathic support they require.

Participants said that other parents of children with similar disabilities offer the most reliable and inspirational source of support. They share a bond that allows for understanding and support at the deepest levels. It is these relationships that can enrich the total life experience, helping parents see the positive aspects of rearing a child with special needs and appreciating their own personal growth. Here's what parents of children with developmental disabilities said:

> *I think the people you meet are so incredible. Other parents—I think that's probably one of the biggest surprises to me. And I had friends before, but somehow my friends who have kids with disabilities are so much more special to me. The warmth, the ability to share very deep feelings at the drop of a hat. And you don't think twice about it because it's such a part of your life.* 15

Special Needs—Advocacy

The fourth subcategory parents discussed was the frustrating necessity for strong advocacy efforts. Many parents reported being unprepared for reality, naively presuming that the system would be more responsive.

> *You really have to be a champion for your children—which is different from what I have to do to raise a biological child.*

> *You do get chewed up and spit out unless you can stand firm in what you believe in. . . . There's nobody who's going to stand by you and say, "This is what you have to do, this is where you have to go, and this is who you have to talk to to get the help you're looking for."*

Special Needs—Finances

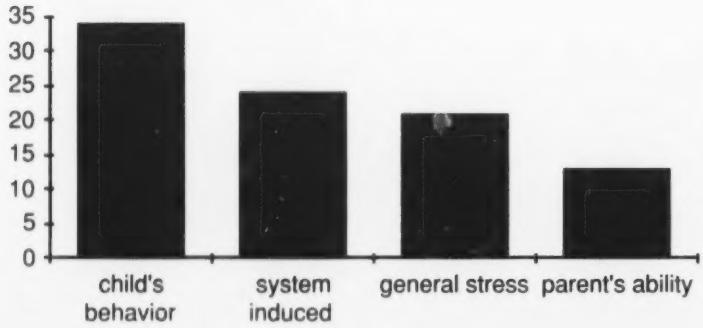
Parents emphasized that children with disabilities often can be a drain on a family's finances. Children with serious emotional disorders usually require intensive, weekly psychotherapy that families cannot always afford and that insurance companies will not always cover.

Pretty soon the insurance company kind of put its hands in the air. They decided the only way they're going to get out of this was by saying he is so bad he's going to have to be committed by the state and have the state pay for it. Otherwise the insurance company realizes they'll have a long-term expensive commitment and they don't want any part of it.

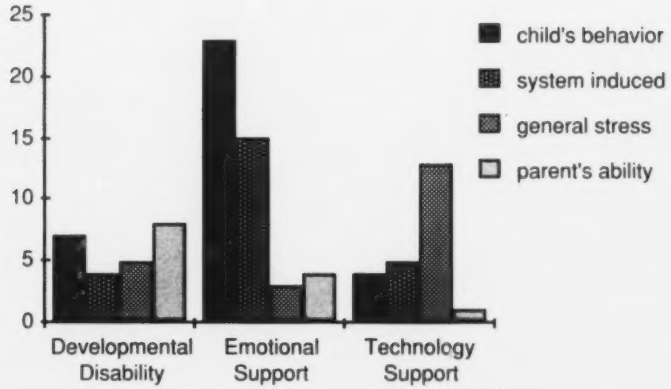
Parents of children with developmental disabilities or technology support reported being eligible for family subsidies and Medicare waivers provided by the state (Leonard, et al., 1989). Still, many were faced with uncovered expenses.

We can barely afford to keep paying for my daughter's medication, which goes up every month.

Statements by Parents - Reasonable Efforts in Crisis Situations



Statements by Parents - According to Disability



REASONABLE EFFORTS IN CRISIS SITUATIONS

Fifty percent of families in this study reported a crisis situation in the preceding six months that threatened the child's placement, confirming that children with disabilities are at high risk.

The most frequently mentioned crisis involved the **child's behavior** and needs, such as depression, running away, not sleeping, or medical problems. Whatever the particular behavior or need, serious consideration was given to addressing the crisis through out-of-home placement.

An interesting finding of this study is that parents' second most frequent statements concerned crisis situations that were, from the parents' perspective, **system induced**. For parents of children with emotional disorders, this occurred when someone outside the family—psychologist, teacher, police officer—decided, despite the parents' wishes, that the child would be better off outside the home. While this outside recommendation could be based on well intentioned concern for meeting the child's therapeutic or educational needs, the parents experienced a crisis because of what they perceived as an intrusion into their family life. This intrusive attitude and approach was seen to stem from a professional orientation toward substitute care as a preferred solution.

You're faced with a situation where you really don't know what's going on with the child and you need to find some answers and they say you need to put him in a hospital.

The school psychologist suggested we see a psychiatrist, . . . and then the school psychologist wanted to call the psychiatrist to say he thought that Laura needed a residential treatment center.

Some parents of children with developmental delays or technology support said system-induced crisis was likely to occur because the system does not run smoothly.

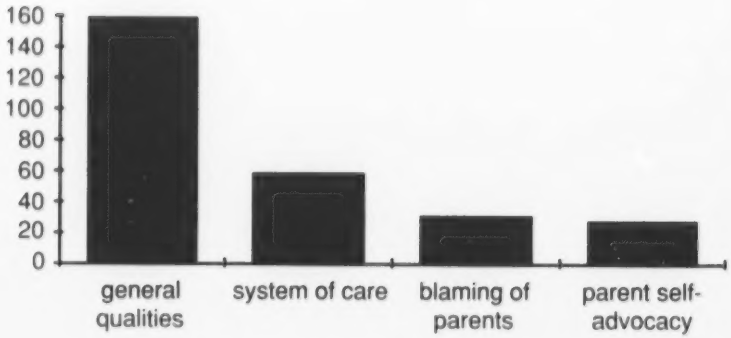
[The crisis comes when] you emotionally burn out. And I don't think you emotionally burn out because of the kids. This is my theory: it's due to the system. The kids are not at fault. The system has to work better.

The third subcategory of crisis parents mentioned was general **stress overload,** including lack of sleep for parents, especially for parents of children with technology support. The daily grind of coping with the child's needs eventually takes its toll.

[A friend] said, "I just couldn't mentally handle diapers. I've been with diapers for ten years. . . . He pulled my hair, he would scratch me, he'd bite me, but it was the diapers that did it." Some things you just cannot handle.

The final subcategory of crisis related to specific, acute situations which impaired the **parents' ability** to provide care for the child. These included physical illness, injury, and family events such as divorce or death of a relative.

Statements by Parents - Relationship with Professionals



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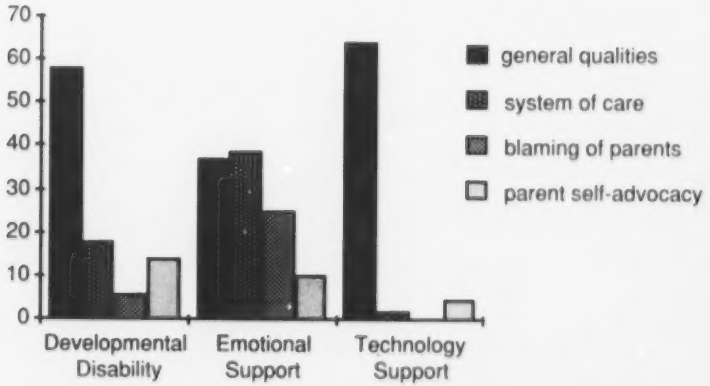

RELATIONSHIP WITH PROFESSIONALS

In discussing their relationships with professionals, participants made a total of 278 statements, which covered four subcategories: (a) general qualities; (b) system of care; (c) blaming of parents; and (d) self-advocacy.

Each disability group had a somewhat different perspective on the **general qualities** most important to their relationship with professionals. Parents of children with emotional disorders emphasized the personal qualities, such as listening, showing respect for parents, and being flexible in scheduling appointments. They didn't feel that professionals totally understood or empathized with the parents and wished that professionals had more hands-on experiences—a "you take this kid home for a week" attitude.

Parents of children with developmental delays stressed the need for professionals' commitment to the child and the family. Too often, workers seemed overwhelmed by caseloads and burned out, so that families only saw them in a crisis. Educators received some praise in this regard because they spent more quality time with the children. Many parents also felt that professionals were too guarded and pessimistic about the child's potential; parents' own higher expectations were generally more accurate.

Parents of children with technology support wanted more help from professionals in gaining knowledge about and access to programs. They also were weary of having to repeatedly educate staff—from physicians to nurse's aides—about their children's unique problems and needs. Parents also valued professionals who understood the family issues and who themselves became a part of the extended family.

Parents also made statements relating to importance of a coordinated, holistic **system of care.** This was particularly relevant for parents of children with emotional disorders:

> *We got a wide variety of views from so-called professionals all the way from school systems on up to doctors on what should be done to my son. . . . Comparing all of these, they all differed. And the majority of them didn't leave us with any specific direction—they would throw things out at you and just leave it hanging.*

In the third subcategory of concern for participants was the perceived tendency of professionals to criticize and **blame parents**.

Parents of children with emotional disorders felt most acutely about this:

The problem happens when you're just a decent, normal set of parents trying to do the best that you can and then you get that same kind of questioning and probing by psychologists and professionals over and over and over again when there isn't anything wrong with your family.

The pain that the biological or adopted parents go through is so incredible to me—the disregard, the way people treat them. And it's your fault, I mean you must have done something wrong, right? Otherwise you would have a good kid like everyone else.

If you disagree with the professionals then you are obstructing their view and you're not compliant and you're dysfunctional.

Parents in other groups were not immune to professionals' scrutiny and criticism:

No other person that does not have a person with a disability is in the limelight and has so many people

looking down on you and saying, "Well, you did this wrong," or "If you had done this." . . . And have you noticed with the therapist there's always a comment that there's something more that you could be doing?

The final subcategory of comments regarding parent/professional relationships reflects parents' dismay at having to be such strong **self-advocates** to professionals. Rather than a helpful, concerned, and cooperative relationship, parents sometimes experience the parent/professional relationship as conflictive and adversarial. Although this issue was discussed by all the groups, parents of children with developmental delays seemed to feel it most strongly:

What you have to do is keep finding out who the supervisors are. You keep climbing the ladder.

My caseworker needs to be kicked in the butt all the time.

You have to sit down and you have to be a master fighter. . . . What's the best strategy to take. And you've got to spend your time thinking about that before you even get to the meeting.

I've found that you have to keep a notebook by the phone. And you have to write down the gist of the conversation because they'll turn around and deny it or say they don't remember.

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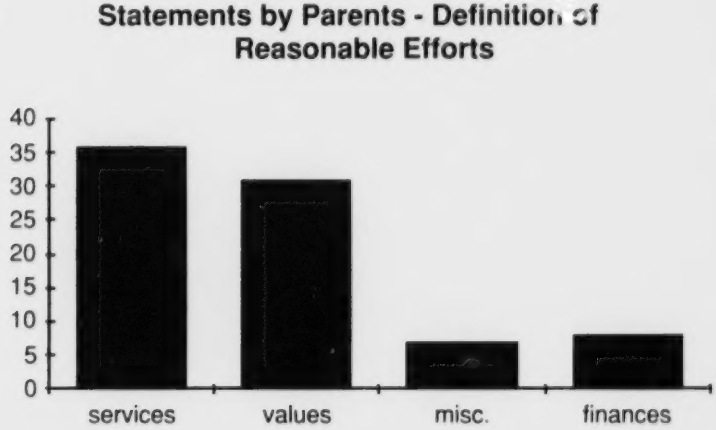
Statements by Parents - Definition of Reasonable Efforts
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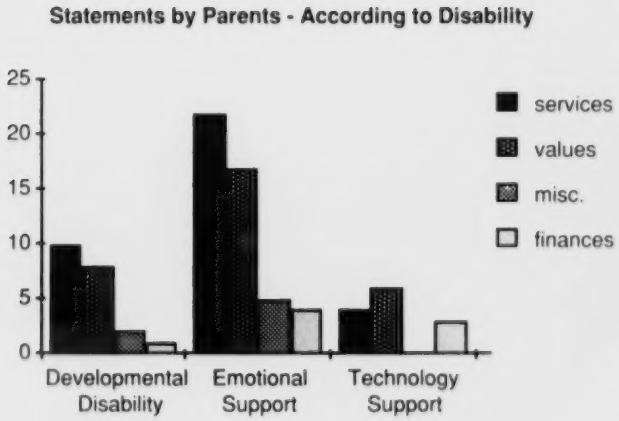
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DEFINITION OF REASONABLE EFFORTS

A few parents had a negative reaction to the term *reasonable efforts*. They seemed to feel that it was somehow a cop-out for the state to claim they made reasonable efforts, and that the state's definition of reasonable would not be as stringent as their own. A parent of a technology-supported child commented:

> *That sounds like a term devised by somebody who's never had a personal, intimate relationship with somebody who's severely sick. There's no such thing as reasonable effort.*

Most of the parents, however, made comments that paralleled and summarized many of the earlier discussions about needs and parent/professional relationships. Participants mentioned the need for **services,** especially respite care; the importance of the proper attitudes and **values;** and the crucial need for **financial support.** Programs should fit their needs, not vice-versa, and should be delivered with a commitment to the value of family.

A parent of a child with an emotional disorder said:

> *Reasonable efforts should include a more holistic approach to the problems of the child and his family.*

Holistic: by that I mean taking into account the educational needs, the psychological needs, the physical needs, the social needs.

A parent of a child with a developmental disability said:

It's reasonable to expect them to be accountable. It's reasonable to expect that what they offer is run efficiently and is indeed serving the needs of the people that it is supposed to be serving. If you're offering everybody a slice of pie, and what they really want is meat and potatoes, that is not the least bit effective.

It's got to start with an attitudinal shift that says people with disabilities are valuable, that families are an integral part of that process.

A key theme mentioned was prevention, voiced most strongly by parents of children with developmental disabilities or with technology support. These parents felt that if services were more readily accessible, crises could be prevented so that the issue of out-of-home placement would rarely come up. This echoes the issue of system-induced crisis.

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[Reasonable efforts] means none of us should have to be doing all of this. It should be done previous to that. And it's really unfortunate that people have to go to the extremes that they do, both timewise, energywise, get demanding like that just to get the services they truly believe are reasonable and ought to be out there.

How much abuse of parents is reasonable for parents to take when they're already dealing with high stress?

Recommended Elements for Definition of Reasonable Efforts

1. ***Continue to focus on provision of services, especially respite care, special education, parent support, and finances.***

2. ***Monitor the values and attitudes of programs and staff.***

3. ***Minimize system-induced crises.***

4. ***Redefine accountability by prioritizing accountability to consumers.***

IMPLICATIONS FOR POLICY AND PRACTICE

As with most exploratory studies, researchers maintain caution in interpreting and drawing conclusions from the data. Nevertheless, the experiences relayed by this active and involved sample from a progressive state can help policymakers and front-line practitioners think about how to improve and extend our reasonable efforts for this population. Specifically, the parent perspective reported here supports incorporating the following elements in a definition of reasonable efforts for children with disabilities:

1. **Continue to focus on provision of services, especially respite care, special education, parent support, and finances.**

A major theme parents mentioned was the need for information about, access to, and competent provision of services.

- Parents deemed respite care essential for both preventing and managing crises.
- Assessment and intervention into special education issues also is a vital, though perhaps currently underemphasized, component of reasonable efforts. (This finding is consistent with recent findings by Barth [1988], who found that special education problems were a critical variable in adoption disruptions and a neglected focus of social welfare intervention.)

- This study supports the encouragement and formation of informal and formal parent support groups.
- Although financial concerns were also prevalent, parents gave them relatively less attention than other needs. This could be unique to this sample, as participants pointed out that Minnesota has a progressive system of family subsidy and Medicare waivers for children with developmental disabilities or medically fragile conditions. Consideration should be given to extending these to children with emotional disorders.

2. Monitor the values and attitudes of programs and staff.

Parents consistently pointed out the critical importance not just of services, but of the values, attitudes, and philosophies behind the way in which services are delivered.

- They want policies and programs that promote normalization and community integration.
- They want a stronger commitment to the goal of maintaining children in their families and communities, especially from professionals they see on a face-to-face basis.
- Participants want professionals to stop blaming and criticizing parents when they don't know how it is to walk in the parents' shoes.

- Parents want professionals to join more fully in the lives of the families, to see and appreciate the positives in their lives, and to relate to them as peers and collaborators rather than as distant experts. This component of reasonable efforts could be implemented through intensive staff training programs that incorporate parents as teachers and spokespersons.

3. Minimize system-induced crises.

As previously discussed, parents believe that many crises are system-induced. Often when professionals recommend placement, parents believe that more, or better, home-based services would suffice. Private insurance is oriented toward reimbursement of inpatient and residential care. Parents become emotionally exhausted from dealing with the system, not from caring for their children. System-induced crises can be minimized by (a) inculcating family-centered values in professionals and addressing financial needs, as discussed above, and (b) by reducing caseloads so that workers can attend to prevention services, not just respond to crises.

4. Redefine accountability by prioritizing accountability to consumers.

Currently, we tend to think of accountability in terms of rules and regulations and procedures. This study reminds

us that it is the consumers to whom practitioners are ultimately accountable. Families feel disenfranchised from the process. The remedy is organized, routine, and regular input from families into the design, implementation, and evaluation of reasonable efforts programs.

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ABOUT THE BEACH CENTER

The Beach Center on Families and Disability is directed jointly by Ann P. Turnbull, Professor of Special Education and Acting Associate Director, Institute for Life Span Studies; and H. Rutherford Turnbull, III, Professor of Special Education and Law, The University of Kansas.

The Center is named after Marianna and Ross Beach of Hays, Kansas, in recognition for their long-standing efforts to support family-focused programs in Kansas, the United States, and Central and South America.

Research projects span the entire life cycle and concentrate on families of persons with developmental disabilities, emotional disorders, and technology support.

The Beach Center publishes a tri-annual newsletter for families and a Publications Catalog. For more information on these items or regarding the Center's research projects, please contact:

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